

OBSERVATIONS

Volunteer Caregivers and the Management of a Total Blind/Brittle Type 1 Diabetic Student and Researcher at Yale

Matthew Weed is a postdoctoral researcher at Yale who has been a labile type 1 diabetic individual since age 1 year and totally blind since age 8 years. He has lived a full life that includes graduating from Yale, Princeton, and Harvard. He has also co-invented tools that help the disabled, has traveled to India, China, and throughout Europe and North America, has completed a roller blading marathon, and works with disadvantaged children.

A unique group of nearly 500 volunteer caregivers has helped Matthew to work, travel, and contribute while learning about the challenges that he has overcome and possibilities that he creates.

Matthew's family helped him monitor his blood glucose and measure his insulin (with limited assistance from teachers) until he graduated from high school. The potential for valuable experience for other students along with the expense of visiting nursing care have encouraged Matthew's universities to offer him the

support needed to recruit caregivers. Students in nearly every discipline and a number of postdoctoral fellows and research scientists have volunteered for Matthew. Further information on recruitment, organization, and training of Matthew's volunteers is in the supplementary materials (available in an online appendix at <http://care.diabetesjournals.org/cgi/content/full/dc10-0880/DC1>).

Under Matthew's direction, the volunteers have monitored his glucose and prepared mixed insulin doses for him twice daily. More care has sometimes been impossible due to problems such as the lack of a glucometer accessible to the totally blind, limited volunteer resources, and the need to balance Matthew's medical needs with his quality of life. Matthew manages his glucose through diet, glucose checks, dosage variation, and frequent exercise.

Matthew's volunteers must engage in a form of closed loop communication with him by verbalizing the steps that they are taking as they prepare the glucometer and insulin dosages. Matthew ensures that steps are taken in the proper order and insulin is measured in the correct amounts.

At no time in the more than 12,000 repetitions of Matthew's routine has a volunteer made an error in measuring insulin that has required clinical intervention to correct. Errors in dosage of less than 3% occur at a rate of approximately 1 time in 200 opportunities. These errors have either been managed via alterations in diet or exercise or by throwing the first attempt away.

Volunteers miss appointments, but at no time have these "misses" exceeded 3% of possible opportunities during any term. Any missed appointments are covered by a highly redundant system that is described in the supplementary materials.

Given proper institutional support, we are convinced that organizations like that which Matthew has created could become a powerful tool in helping students in health care and other disciplines learn about and develop empathy for the needs of the chronically ill and disabled while training them to care for this rapidly growing patient population. They could also safely, effectively, and inexpensively reduce a small part of the strain on our health care system that long-term care imposes and help the chronically ill and disabled to learn, grow, work, and contribute to our society.

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